Final Evaluation

HIV/AIDS IMPACT Mitigation through Mobilizing Affected Communities Project

Kanchanpur District Nepal

Submitted to the Save the Children USA, Himalayan Field Office

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Executive Summary

In May 2003, evaluators were engaged by Save the Children USA (SC/US) to conduct a final evaluation of the *HIV/AIDS IMPACT Mitigation through Mobilizing Affected Communities Project* in Kanchanpur District, Nepal. SC/US undertook this evaluation as a part of their funding agreement with the United States Agency for International Development (USAID) and to document the project's experiences and lessons learned.

The HIV/AIDS IMPACT Mitigation through Mobilizing Affected Communities Project in Kanchanpur District was funded from June 14, 2001 to June 13, 2003 by USAID, to reduce the susceptibility and vulnerability of children and families to HIV/AIDS in communities from where male migration to India is endemic. This was attempted through capacity building, community mobilization, development of community program options, creation of referral and linkage systems, and the initiation of care and support activities. The implementation of this project was undertaken by SC/US in partnership with two local non-governmental organizations (NGOs): the Nepal Red Cross Society (NRCS) and the Nepal National Social Welfare Association (NNSWA).

To help assure a systematic exploration of project performance, an evaluation matrix using four accepted criteria was developed to organize key questions and data collection: (1) **Relevance**, (2) **Effectiveness/Efficiency**, (3) **Impact**, and (4) **Sustainability**. The findings and recommendations of this evaluation are organized by these four criteria.

Relevance:

The evaluation findings...

- 1. The project was relevant to a growing need for HIV/AIDS community-based impact mitigation in Kanchanpur District. It was also successful in developing synergies with other relevant projects, bodies and activities in the district.
- The building of district- and community-level support for this project through awareness raising and sensitization was a pre-condition of success for this project. Had the project attempted to mitigate the impact of HIV/AIDS at the community level without first dealing with the existing levels of ignorance, denial, stigma and discrimination, the project would not have been successful.
- 3. Given the project's success in eliminating stigma and discrimination, there is now an opportunity to more fully engage affected households. Given increased partner skills in engaging with these households, this can be done in a manner that does not create unrealistic expectations of project delivery.
- 4. Original misunderstandings of the purpose of the project were related in part to the project being unable to deal with priority issues (i.e. income generation, support for affected households) identified by the target communities in the rapid assessment.
- 5. The project would have benefited from an initial planning workshop for partners to develop and agree upon a shared understanding of the project, including the key concepts of "impact mitigation" and "care and support", and to develop a communication plan for disseminating this understanding to stakeholders and the wider community.
- 6. The relevance of referral and linkage systems are related to whether the systems can put people in contact with the services that they require (i.e. care and support, VCT, income

generation). When such systems are developed, they must not only include available services but also consider the inclusion of services identified and required by the communities.

7. Prevention activities must be integrated in HIV/AIDS impact mitigation projects as a part of a prevention to care continuum.

The evaluation recommendations...

- 1. Any future major impact mitigation project in Kanchanpur should build upon and continue the awareness building and sensitization work of this project.
- 2. Any future major impact mitigation project in Kanchanpur should include a size estimation of the households affected by HIV. It is also recommended that a study be undertaken of the sexual behaviors of migrant men while residing in Kanchanpur.
- 3. Any future impact mitigation project in Kanchanpur should engage affected households and their members in needs identification, and project design and implementation. Involvement in implementation could include both governance and delivery.
- 4. Any future impact mitigation project should ensure clarify of its objectives with beneficiary communities and stakeholders prior to implementation. This should include clarification of the project's relationship with those who are affected by what are considered HIV/AIDS opportunistic infections (e.g. TB, ARI, diarrheal diseases) and require care and support but who may or may not have HIV/AIDS.
- 5. Any future major impact mitigation project in Kanchanpur should work to ensure that community needs for on-going prevention services, VCT, expanded care and support, and income generation opportunities are met either within or outside the project.

Effectiveness/Efficiency:

The evaluation findings...

- 1. The project has successfully achieved its deliverables and reached the targeted beneficiaries. This success can be attributed to the project's strategy of awareness building, mobilization, and development of district bodies, community organizations, and care providers throughout the life of the project. This was essential to develop district and community level support and advocacy for the project. The building of partner and care provider capacity, the use of experienced local partners, and the efforts expended on coordinating stakeholders were also important factors.
- 2. The project, through its work to reduce stigma and discrimination, has created an opportunity for people who are HIV+ and their families to become fuller participants in the process of both defining their status as beneficiaries and determining their needs.
- Because of the large number of stakeholders involved and the use of referrals and linkages to match affected households with needed services, large coordination efforts were required.
- 4. Any project that mobilizes FCHVs should also mobilize Maternal and Child Health Workers (MCHW), as the primary support structure for the FCHVs.

- 5. There is an opportunity for a community-based impact mitigation project to provide affected households with "legacy support", helping terminally ill parents to plan for their children's well-being and future (e.g. guardianship, inheritance, family unity).
- 6. Pilot projects need to be explicitly designed as such: formalizing and documenting learning. Without this explicit understanding, project staff is committed to the implementation of project activities, without the parallel obligation to reflect on their implementation in an organized and systematic manner.

The evaluation recommendations...

- 1. The project staff of the HIV/AIDS Impact Mitigation through Mobilizing Affected Communities Project should conduct a facilitated review exercise to analyze and document the experiences of this project, and suggest how the programming approaches used could be replicated or expanded. Such a review should also identify the unmet needs of affected and vulnerable households.
- 2. Any future major impact mitigation project in Kanchanpur should include (1) a needs assessment of care and support requirements, (2) the development of a shared understanding of community-based care and support, and (3) a framework to assist communities to develop their own options and to set priorities for resource allocation. A clear linkage should also be established with VCT and prevention programming. Such a future project must be built upon a base of aware, supportive and mobilized communities and district stakeholders.
- 3. Any future major impact mitigation project in Kanchanpur should include the development and availability of technically proficient and experienced staff to train and support community- and home-based care-providers (including counselors). Such expertise could be developed either within district-based project staff or within the office of the DPHO. There is a need for the counseling centre at the Mahakali Zonal Hospital to become more accessible and physically welcoming, and able to offer prevention services.
- 4. Any future impact mitigation project in Kanchanpur should include the capacity building of MCHWs and the development of "legacy support". Any future referral system should include links to adjacent Indian testing and treatment facilities. This would be particularly important for Chandani and Dodhara VDCs, where people normally access Indian health services because of their proximity.
- 5. Any future impact mitigation project Kanchanpur should involve affected households in project implementation, including governance and delivery. Specific activities for consideration include the employment of people with HIV in the project, the use of HIV+ volunteer peer workers, the establishment of a project advisory group of affected households, and the use of participatory monitoring and evaluation methodologies with beneficiary affected households.
- 6. Any future major impact mitigation project in Kanchanpur should integrate the lessons learned from this project on the use of local partners, including role delineation.
- 7. Any future major impact mitigation project in Kanchanpur should develop and apply standard project management tools and ensure partner compliance with these tools.

Impact:

The evaluation findings...

- 1. The project has appeared to reduce the vulnerability of affected households and increase their well-being. Partner NGOs and community bodies exhibited newly developed capacity to support community efforts to assist affected households.
- 2. The project's work to reduce stigma and discrimination was critical to developing the enabling environment required for communities to mitigate the impact of HIV/AIDS. The use of PLA and PRA methodologies were an important component in increasing awareness, and reducing stigma and discrimination. This has created an opportunity for a fuller involvement of people with HIV and their families in the project.
- 3. Involvement of local government and community bodies was important to create ownership of community-based impact mitigation activities.
- 4. An unintended impact of the project's awareness building and stigma and discrimination reduction efforts was an increased community demand for VCT and increased care and support, including drugs for opportunistic infections.
- 5. An unintended impact of the project's community mobilization activities was the desire of community bodies (i.e. VACC/MACC) to engage in impact mitigation activities using their own resources. It would be important next step to develop the capacity of these bodies to formally engage their communities to assess needs, set priorities, and make plans on how to best use their limited resources. It would also be important to further develop their capacity to coordinate with community and external bodies.

The evaluation recommendations...

There are no recommendations specific to this section.

Sustainability:

The evaluation findings...

- Community and local government bodies have expressed willingness and demonstrated an ability to carry on the work of the project (with the exception of the central counseling centre) within the limits of their capacity and resources. There remains some concern of the planning capacity of community bodies to assess community needs, set priorities, and commit resources.
- 2. There is a need for more time and resources to "set" the project's successes.
- 3. There are concerns about the ability of poor communities to deliver impact mitigation services, including community-based care and support, as the epidemic increases in size. Community reliance on fund raising and a charity model may not be sustainable given the limited funds available in the community. There are also concerns about the level of responsibility that can be placed on community volunteers to deliver services.
- 4. Sustainability of the project is threatened by a lack of income generation and employment opportunities.

- 5. If the project were to be expanded, there would be a need to systematically develop the services required by the community and to ensure their delivery either within or outside the project.
- 6. With the project focus on the creation of an enabling environment, it is inevitable that community demand for impact mitigation will increase. As such, the sustainability of this project is linked to the ability to expand the project to include these needed services. The replication of this project in other parts of Kanchanpur District would also result in increased demands for these services.
- 7. Despite past challenges, there is a need to fully engage the public health system. The ongoing operationalization of the *National HIV/AIDS Strategy* may provide some direction and support in the areas of prevention of HIV/AIDS among migrants and their families, VCT, PMTCT, protocols on the management of opportunistic infections, and social protection for people who are HIV+ and their families.

The evaluation recommendations...

- 1. Any future impact mitigation project in Kanchanpur District should continue to build the capacity of community bodies to plan. This includes the capacity to assess needs, set priorities and commit resources, as well as coordinate with stakeholders.
- 2. Any future major impact mitigation project in Kanchanpur should assess the capacity of poor communities to support an increasing number of affected households. An assessment should also be conducted on the level of responsibility that should be placed upon community volunteers and what support systems are required.
- 3. Any future major impact mitigation project in Kanchanpur should review the linkages between the project and the public health system, including the NCASC. As elsewhere, there is the dilemma of whether to build the capacity of an under-performing system or to build local capacity outside or parallel to the public system. This includes questions of whether communities should be generating funds for OI treatment, or NGOs should be delivering care and support, counseling and VCT services. These issues go far beyond this project but should be addressed in the absence of a response from the public health system. The project should be prepared to create synergies with the impending operationalized National HIV/AIDS Strategy.
- 4. Any future impact mitigation project in Kanchanpur should move community bodies and volunteers from a primary focus on fund raising, to one that includes advocacy and the promotion of self-help, better using existing community resources. Following the example of Daijee VACC, more analysis is needed on the use of community resources to pay for the drugs required for opportunistic infections and palliative care.
- 5. Any future impact mitigation project in Kanchanpur should be an <u>expansion</u> and not a <u>replication</u> of this project. Given increasing awareness and the resulting increasing demand for services, an expanded project should ensure that VCT, prevention services, expanded community-based care and support, and income generation and employment opportunities are available. Such an expansion should be built upon the awareness, acceptance, built capacity, and mobilization of the current project, but should also involve a more systematic needs assessment, a framework for service delivery of community-based care and support, and technical support to care providers.

Acknowledgements

This evaluation would not have been possible without the cooperation of a great number of people. The evaluators would like to firstly thank Tara Karki Chettry of the Kathmandu Field Office of Save the Children USA for her assistance in organizing the evaluation and field visit. Secondly, the success of the field visit would not have been possible without the assistance and candor of the Project Coordinator, Lok Raj Bhatta. The observers from Family Health International, Jesper Svendsen and Barat Mani Pant provided the evaluators with valuable input on HIV/AIDS care and support. The Project Coordinators for the partner NGOs, Manoi Bhatta of the Kanchanpur chapter of the Nepal Red Cross Society (NRCS) and Bhim B. Simal of the Nepal National Social Welfare Association (NNSWA) also provided the evaluators with access to all aspects of project implementation and gave freely of their time and opinions. Many project staff from the NRCS and the NNSWA, as well as local government officials and community leaders were also generous with their time and opinions, and allowed us to observe their work. Finally, a sincere and humble acknowledgement of the many community members, particularly those living with HIV/AIDS and their families, who welcomed us into their lives and homes, and shared patiently and with dignity, their stories on the impact of HIV/AIDS on their communities.

It is our intention and hope, as evaluators that this report presents the information and views received during our field visit, with the same honesty and respect that were accorded to us.

Acronyms

AIDS Acquired Immune Deficiency Syndrome

BCC **Behaviour Change Communication**

DACC District AIDS Coordination Committee

District Public Health Officer **DPHO**

FCHV Female Community Health Volunteer

GIPA Greater Involvement of People with AIDS

HIV Human Immuno-deficiency Virus

HIV+ **HIV Positive**

J/YRCC Junior/Youth Red Cross Circle

MACC Municipal AIDS Coordination Committee Maternal and Child Health Worker

MCHW

NCASC National Centre for AIDS and STD Control

NGO Non-Governmental Organization

NNSWA Nepal National Social Welfare Association

NRCS Nepal Red Cross Society

OI Opportunistic Infections

OVC Orphaned and Vulnerable Children

PASC Project Advisory and Support Committee

PE Peer Education/Educator PHC Primary Health Centre

Participatory Learning and Action PLA

Prevention of Mother-to-Child Transmission **PMTCT** P/NGO Partner Non-Governmental Organizations

PRA Participatory Rural Appraisal

Peer Worker PW

Save the Children USA SC/US

STD/STI Sexually Transmitted Disease/Infection

USAID United States Agency for International Development

VACC Village AIDS Coordination Committee **VDC** Village Development Committee VCT Voluntary Counseling and Testing

WBS Work Breakdown Structure

1. Introduction

In May 2003, Brian Gilligan and Dr. Pulkit Choudhary were engaged by Save the Children USA (SC/US) to conduct a final evaluation of the *HIV/AIDS IMPACT Mitigation through Mobilizing Affected Communities Project* in Kanchanpur District, Nepal. SC/US undertook this evaluation as a part of their funding agreement with the United States Agency for International Development (USAID) and to document the project's experiences and lessons learned.

1.1 Project in Brief

The HIV/AIDS IMPACT Mitigation through Mobilizing Affected Communities Project in Kanchanpur District, was funded from June 14, 2001 to June 13, 2003 by USAID, to reduce the susceptibility and vulnerability of children and families to HIV/AIDS in communities from where male migration to India is endemic. This was attempted through capacity building, community mobilization, development of community program options, the creation of referral and linkage systems, and the initiation of care and support activities. As a short-term project, intended to pilot community-based HIV/AIDS mitigation approaches, it was limited to half of the wards in four Village Development Committees (VDCs) and one municipality.

The implementation of this project was undertaken by SC/US in partnership with two local non-governmental organizations (NGOs): the Nepal Red Cross Society (NRCS) and the Nepal National Social Welfare Association (NNSWA). The funding for this project was US\$266,660 of which US\$200,000 was provided by USAID as a grant. The period of funding for the local partners was from December 1, 2001 to June 13, 2003, for 18 months of programming.

1.2 Evaluation Purpose and Scope

The primary purposes of this evaluation were to assess the impact of the project, highlight the lessons learnt, and serve as a basis for any future planning to undertake related projects.

The scope of the evaluation included community mobilization, male involvement as educators, effectiveness of the District, Village and Municipal AIDS Coordinating Committees (DACC, VACC and MACC), home-based care, counseling, referral networks, behavior change communication, capacity of partner NGOs, advocacy, sustainability, and linkages.

The objectives of the evaluation, as listed in the terms of reference, included instructions to:

- Assess the changes in communities knowledge, attitude and behavior and compare this knowledge with baseline knowledge from the rapid assessment
- Identify gaps, barriers and constraints of implementation, and determine why these gaps/barriers/constraints occurred, and how they can be resolved
- Assess the impact of the program in the communities in terms of care and support, stigma and discrimination, and VCT implications. Determine which strategies were most effective in changing knowledge, attitude and behavior of target groups, stakeholders and key decision-makers. WHY were these strategies most effective?
- Assess quality of program management of SC/US and P/NGOs, including supervision, monitoring and assessment of feedback given by both parties
- Assess how the program has addressed sustainability.

- Assess capacity of NGOs and determine which capacity building activities were most effective. Determine additional capacity building needs.
- Identify lessons learned in the project, suggesting reasons for particular successes and failures. Suggest mechanisms and approaches to share lessons learned with a wider audience. Suggest how these lessons learned can be used in other districts.
- Assess the appropriateness of project management, project resource use.

1.3 Evaluation Methodology

The evaluation began with a desk review of project documents and interviews with key SC/US staff in Kathmandu, as well as with members of the Nepal office of Family Health International (FHI). FHI staff, at the request of USAID, accompanied the evaluation team to the project site.

Between June 1 and June 6, 2003, guided by an approved evaluation work plan, the evaluation team (1) interviewed the SC/US Regional Program Manager in Nepalgunj, (2) interviewed SC/US, NNSWA and NRCS project staff in Kanchanpur, (3) interviewed local public officials, community leaders, activists, service providers and recipients, (4) conducted focus group discussions with community members, and (5) visited project sites.

Table 1: Summary of Interviews/Focus Groups and Site Visits

Participants Involved and Sites Visited	Number
Save the Children USA	5 staff; 3 sites
Family Health International and Care Nepal	4 staff
Nepal Red Cross Society	3 staff; 2 sites
Nepal National Social Welfare Association	2 staff; 3 sites
6 Mothers' Groups – Focus Group Discussions	125 members; 6 sites
Jhalari VDC Female Community Health Volunteers – Focus Group Discussion	24 FCHVs
Female Community Health Volunteers	3 FCHVs
Heads of Households affected by HIV/AIDS	9 (8 women; 1 man)
Mahakali Zonal Hospital	2 staff
Main Counseling Centre and 2 Peripheral Counseling Centres	2 staff; 3 sites
Chief District Officer, Local Development Officer, District Public Health Officer	3 staff
4 Village AIDS Coordinating Committees	45 members; 4 sites
Traditional Healers	2 healers; 2 sites
Male Peer Workers	13 members; 2 sites
3 Youth/Junior Red Cross Circles and Teachers – Focus Group Discussion	62 members; 2 sites

A complete schedule of those interviewed and the sites visited is included in **Appendix A**

The evaluators were able, following the work plan, to meet with a range of people involved in the projects and gain a broad view of its work and impact, as well as its lessons learned.

To assure these inquiries systematically explore project performance, an evaluation matrix using four accepted criteria was developed to organize key questions and data collection.

Relevance: Is there a need for the project?

Effectiveness/Efficiency: Did the project deliver what it said it would to its intended targets? Was the delivery efficient, making the best use of project staff, funds and time? **Impact:** What are the project's lasting results, intended and unintended? **Sustainability:** Ability of project partners, stakeholders and beneficiaries to continue the work of the project? Is there potential for the project to be "scale-up" and expanded?

1.4 Evaluation Limitations and Challenges

In delivering this evaluation, the evaluators identified several limitations and challenges.

- 1. This evaluation was intended as a final evaluation with an expressed goal of measuring the impact of a project that <u>only</u> delivered 18 months of programming. While it was recognized that this was to be a *qualitative* assessment, it was also expected that impact would be assessed. In the absence of an initial baseline study, all conclusions drawn by the evaluators are only indicative of possible impact.
- 2. While SC/US staff clearly stated that this was a "pilot project", intended to engage local governments, communities and care providers, and to test approaches to community-based impact mitigation, the project documentation did not articulate this approach.
- 3. During the project design period, the key terms "impact mitigation" and "care and support", as well as delivery targets, were not defined. In addition, several important project management tools were never developed, making it complicated to measure project delivery and results achievement.

The evaluators were unable to meet with out-of-school peer educators and private care providers due to time limitations. It is felt that this did not adversely affect the report.

1.5 Organization of the Report

Table 2: Report Organization

Exe	Executive Summary		<u>Appendices</u>	
Acl	Acknowledgements			
Abl	Abbreviations 1. Introduction		People, Groups and Facilities Visited	
1.			Summary of Deliverables to Date	
	1.1. Project in Brief			
	1.2. Evaluation Purpose and Scope			
	1.3 Evaluation Methodology			
	1.4 Evaluation Challenges			
	1.5 Organization of the Report			
2.	Project Description			
	2.1 Background			
	2.2 Disbursements to Date			
	2.3 Monitoring and Reporting			
3.	Relevance			
4.	Effective/Efficient			
5.	Impact			
6.	Sustainability			
7.	Conclusions			

Placed throughout this document are text boxes with the title "Lesson Learned". These indicate areas of learning identified by project staff. To acknowledge the project's ownership of these lessons, they have been placed in text boxes.

2. Project Description

2.1 Background

The project's stated objective was to minimize the impact of HIV and AIDS on children and families of men who migrate to India from Kanchanpur District. This was to be accomplished through community mobilization, capacity building, the development of program options for working with communities, and the initiation of community-based care and support activities for people with HIV/AIDS and their families. The unstated objective was to pilot approaches to achieve the above.

The strategies identified for use in this project included:

- Awareness raising
- Community consciousness, participation and mobilization
- Male involvement
- Integration of pre-existing structures, systems and programs
- Partnership with NNSWA, NRCS and local government
- Direct work with children and adolescents
- Capacity building
- Advocacy and creation of a non-stigmatizing and non-discriminatory environment

These strategies were implemented by SC/US's local partners: NNSWA and NRCS, with SC/US providing a capacity building and coordination function. Three project coordinators from SC/US, NNSWA and NRCS and ten community mobilizers from the NNSWA and NRCS undertook the work, supported by numerous community volunteers, as well as public and private health and social welfare service providers. The long histories of the partners in Kanchanpur and their established presences were viewed as critical to project success.

The implementation of the project occurred in approximately half of the wards in Chandani, Dodhara, Daijee, and Jhalari VDCs, and in Mahendra Nagar Municipality. In implementing the project, the partners were to work with existing structures, organizations and volunteers; public, private and traditional health service providers; and, local governments, in order to find synergies and linkages with existing projects and services to most efficiently use available resources to mitigate the impact of HIV/AIDS on the targeted communities.

In designing the project, a number of conditions were placed on the project:

- Funding was for 18 months of programming (24 months with the rapid assessment).
- No baseline study of HIV prevalence or risk behaviour was conducted.
- No provision of prevention or income generation programming.
- Use of existing structures to deliver community-based care and support activities.
- No provision of Voluntary Counseling and Testing (VCT); community members were not to be encouraged to investigate their HIV status through private laboratories.
- Support for community-created options for home-based care and support was not to include the provision of drugs or medical supplies for opportunistic infections (OI).

These conditions created several expected and unexpected challenges for the project as it attempted to achieve the project's **Intermediate Results** and **Expected Outcomes**, within the 18-month project period. These results and outcomes were:

Intermediate Results:

1. Program options to work with families vulnerable to HIV/AIDS identified by migration.

- 2. Increased capacity of local NGOs to facilitate and support community efforts to provide care and support for people living with HIV and their families, including children.
- 3. Increased capacity of the community to support households affected by HIV/AIDS.

Expected Impact (at the end of 2 years):

- 1. Increased access and utilization of counseling and care (institutional and home based) services by PLWHAs and their families
- 2. VACCs have developed and instituted (structures and systems in place) realistic plans for protection, care and support of vulnerable and/or affected households
- 3. District level and peripheral level counseling services and referral system set up
- 4. DACC/DDC replicate the project approaches in other VDCs of Kanchanpur District.

Implementation challenges in the initial months of the project required considerable rethinking on the project's purpose. Faced with district level resistance and denial, limited community awareness of HIV/AIDS, and high levels of active discrimination against those who were HIV+ and their families, the project refocused its initial efforts on building awareness (including for prevention) and combating community-level fears and misconceptions about HIV/AIDS. Without building a solid base of aware and supportive communities, the project would not have been able to mobilize communities to generate and implement options to mitigate the impact of HIV/AIDS on affected families, including home-based care and support. There was also an unexpected requirement to "remobilize" many of the Mothers' Groups that the project had expected to use, as many of these groups had become inactive since the completion of an earlier CARE Nepal project.

2.2 Disbursements to Date

The USAID grant disbursements were divided into two phases: June 14, 2001 to September 30, 2002, and October 1, 2002 to June 13, 2003. In Phase 1 **US\$100,948.14** was spent, while in Phase 2, **US\$99,051.86** was spent, giving a total expenditure of **US\$200,000**.

2.3 Monitoring and Reporting

As a result of the absence of several standard management tools and systems, the monitoring of project and its performance was uneven and difficult to follow.

In the planning documents there was no work done to link the long list of process and outcome indicators in the Monitoring and Evaluation Framework to specific results. There was also no creation of a work breakdown structure (WBS), or division of project activities into components, activity sets or work packages. In the quarterly reports, without a WBS it was difficult to understand the organization of activities. In addition, the lack of cumulative reporting and activity-based financial reporting made it difficult to track progress over time.

The absence of such tools and systems did not appear to adversely affected programming, though there would have been some loss of project efficiency. This was probably due to the project's small size. Any decision to expand this project, however, would require a much more rigorous approach to project management, including the development and use of standard project management tools. This is discussed in more detail on Page 15.

3. Relevance

Is there a need for the project? How was the initial situation assessed?

It is prudent to begin by noting that in the absence of complete national HIV/AIDS surveillance data, no definitive statements can be made on the general prevalence of HIV in Kanchanpur, or even among families affected by labour migration to India. The project's initial rapid assessment, in determining the needs of those infected and affected by HIV in Kanchanpur, was only able to locate 23 self-identified suspected HIV+ individuals willing to discuss their situations. There remains a considerable need for sero-and behavioral surveillance of migrants and their families both in India and Nepal. However, given the current projections from the National Centre for AIDS and STD Control (NCASC) and an accepted link between migration and HIV/AIDS¹, it can be assumed that there is a considerable risk of HIV infection among Kanchanpur communities affected by male migration to India, particularly Mumbai. The real figure, while unknown, is undoubtedly more that the Mahakali Zonal Hospital's 101 confirmed cases of HIV/AIDS.

Given both the probable large number of HIV infections in Kanchanpur and the project's objective, it does appear noteworthy that only a small number of people have been identified by the project as infected or affected by HIV over the last 18 months (38 families, including 90 children). In discussions with project staff, this "shortfall" was explained in the following ways:

- **Firstly**, an initial lack of awareness and high levels of stigma, stopped people from seeking support; in turn, the project needed to focus its initial efforts on building a more supportive community environment in which HIV status could be safely disclosed.
- **Secondly**, the project was instructed not to actively seek out those people who were potentially infected or their family members.
- **Thirdly**, as it was a pilot project, focusing on the building of an enabling environment and engaging local governments and service providers, it was believed that the project was developing a foundation for a larger response to a growing epidemic.

18 months after the beginning of the project, Kanchanpur District officials and target communities are unanimous in their belief that HIV/AIDS is now a significant health, social and economic issue, and support SC/US's focus on developing impact mitigation approaches at a community level. The mobilization and active participation of DACC, four VACCs, and the MACC in the project would appear to confirm this belief.

While there appears to be some weaknesses with the initial rapid assessment, particularly on the need for the project, it was probably sufficient given the conditions in Kanchanpur District in 2001 (i.e. lack of awareness, district and community resistance, stigma and discrimination) and the limitations placed upon the project. It was noted that little effort was made during the assessment or the project to apply the *Greater Involvement of People with AIDS* (GIPA) principle in project planning and implementation. The reasons given were the level of community stigma at the beginning of the project and the resulting unwillingness of those infected or affected by HIV/AIDS to play such a role. Several staff also expressed reservations about involving affected households as full participants because they feared creating unrealistic expectations of what the project could deliver.

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¹ In discussions with the four project VACCs, it was estimated that between 40% of 60% of males in their VDCs were migrant workers in India.

Were the project's objectives sufficiently clear?

While discussions with some local government officials revealed some misunderstandings of project objectives, for the most part, communities expressed a consistent and accurate understanding of the project. Initially, there was a significant expectation by community members and leaders that the project would provide income generation opportunities and financial support for vulnerable households; a need clearly identified in the rapid assessment. The adjustment of this expectation required significant effort in the initial months of the project.

Project staff raised several concerns with regard to the project's objectives and the unplanned efforts that were initially required to build awareness (including prevention), reduce stigma and discrimination by community members and health workers, and, mobilize communities and local government bodies. It was also felt, in retrospect, that the project should have dealt more directly with the poverty of vulnerable households, as identified in the rapid assessment.

An additional concern on clarity of objectives was the relationship of the project to those community members who were not HIV+ but were suffering from illnesses normally termed "opportunistic infections" (i.e. tuberculosis, acute respiratory infections, etc...). While community members appeared to have access to care for these illnesses, regardless of their HIV status, this idea was not developed in the initial project documentation. It is an important concept at this stage in Nepal's HIV epidemic, as most people who suffer from these ailments are not HIV+, and most people who are HIV+ do not have a confirmed (i.e. tested) sero-status. This issue would appear to be related to the lack of VCT facilities in Kanchanpur.

Given the pilot project nature of the project, it would seem normal to invest considerable staff time in reviewing the project's purpose and work, during the project's lifetime. It does not appear, however, that a process was established to formalize, document and disseminate the many important lessons learned. It also appears that a shared understanding was never developed of the key project concepts "care and support" and "impact mitigation".

Was there a synergy between the project and other relevant projects, bodies and activities in the region?

Given the limited time and resources of this project, as well as its various conditions, it was critical to coordinate with other stakeholders and to create links to their activities, in order to efficiently access resources and build support for common purposes. The project's referral and linkage systems were intended to connect families affected by HIV with the necessary health, counseling and social (i.e. education, job training) services. It was evident during the field visit that considerable efforts had been made in developing these synergies.

- <u>Project Advisory and Support Committee (PASC)</u>: Able to search and exploit opportunities for synergies. The PASC included the chair of DACC, the SC/US, NRCS and NNSWA project coordinators, one Village AIDS Coordinating Committee (VACC) chair, and a representative from the CARE Nepal Child Survival Project.
- <u>District AIDS Coordination Committee (DACC)</u>: DACC helped the project to work with Mahakali Zonal Hospital, as well as connect affected households to education and skill development funds and projects.
- Enhanced Support for HIV Prevention in Nepal Project: This NEDA-funded project provided prevention support to the project until its completion in September 2002.

- CARE Nepal's Child Survival Project: Synergies with the training of Female Community Health Volunteers (FVHV) and Maternal Child Health Workers on some opportunistic infections, antenatal care, hygiene/sanitation, and nutrition.
- <u>Highway Project:</u> The establishment of "storefront" STI clinics by this project, increased access to STD services for Kanchanpur residents.
- Adolescent Reproductive Health Project: Training links for peer educators with this other SC/US project.
- <u>SC/US NNSWA Partnership Sponsorship Program:</u> The pre-existing relationship between SC/US and NNSWA in the management of SC/US's Sponsorship Program in Kanchanpur, facilitated the project to access the community development and education components of the sponsorship program.
- Miscellaneous Linkages: Project synergies with the District Education Office and skill development centres provided resources to affected families.

In reviewing these linkages, two issues were clear. The first was that many links were dependent upon donor-funded projects of limited duration. The second was that the limits of district level support for affected and vulnerable families remain uncertain, particularly in the face of a widening HIV/AIDS epidemic.

The relevance of a project that desires to create referrals and linkages will be undermined if needed services identified by the community in the initial assessment (i.e. income generation) or during the life of the project (i.e. VCT, drugs for opportunistic infections) are neither available nor accessible. The success of the project in building awareness and reducing stigma and discrimination created a demand for increased community-based care and support services. If these services cannot be offered in the near future in a sustainable manner to the people who require them, the referral and linkage systems established by the project may lose their relevance.

The relevance of the project is also potentially undermined by the absence of an ongoing and accessible source of prevention services. While the project was able to build upon and provide referrals to the *Enhanced Support for HIV Prevention in Nepal Project*, this point in the referral system was removed with its completion in September 2002.

Lesson Learned:

A care and support system should be developed in the context of a prevention to care continuum. HIV/AIDS referral systems must have access to prevention programming.

3.1 Findings and Recommendations

The evaluation findings...

- 1. The project was relevant to a growing need for HIV/AIDS community-based impact mitigation in Kanchanpur District. It was also successful in developing synergies with other relevant projects, bodies and activities in the district.
- 2. The building of district- and community-level support for this project through awareness raising and sensitization was a pre-condition of success for this project. Had the project attempted to mitigate the impact of HIV/AIDS at the community level without first dealing with the existing levels of ignorance, denial, stigma and discrimination, the project would not have been successful.

- Given the project's success in eliminating stigma and discrimination, there is now an
 opportunity to more fully engage affected households. Given increased partner skills
 in engaging with these households, this can be done in a manner that does not create
 unrealistic expectations of project delivery.
- 4. Original misunderstandings of the purpose of the project were related in part to the project being unable to deal with priority issues (i.e. income generation, support for affected households) identified by the target communities in the rapid assessment.
- 5. The project would have benefited from an initial planning workshop for partners to develop and agree upon a shared understanding of the project, including the key concepts of "impact mitigation" and "care and support", and to develop a communication plan for disseminating this understanding to stakeholders and the wider community.
- 6. The relevance of referral and linkage systems are related to whether the systems can put people in contact with the services that they require (i.e. care and support, VCT, income generation). When such systems are developed, they must not only include available services but also consider the inclusion of services identified and required by the communities.
- 7. Prevention activities must be integrated in HIV/AIDS impact mitigation projects as a part of a prevention to care continuum.

The evaluation recommendations...

- 1. Any future major impact mitigation project in Kanchanpur should build upon and continue the awareness building and sensitization work of this project.
- 2. Any future major impact mitigation project in Kanchanpur should include a size estimation of the households affected by HIV. It is also recommended that a study be undertaken of the sexual behaviors of migrant men while residing in Kanchanpur.
- 3. Any future impact mitigation project in Kanchanpur should engage affected households and their members in needs identification, and project design and implementation. Involvement in implementation could include both governance and delivery.
- 4. Any future impact mitigation project should ensure clarify of its objectives with beneficiary communities and stakeholders prior to implementation. This should include clarification of the project's relationship with those who are affected by what are considered HIV/AIDS opportunistic infections (e.g. TB, ARI, diarrheal diseases) and require care and support but who may or may not have HIV/AIDS.
- 5. Any future major impact mitigation project in Kanchanpur should work to ensure that community needs for on-going prevention services, VCT, expanded care and support, and income generation opportunities are met either within or outside the project.

4. Effectiveness/Efficiency

Did the project deliver what it said it would to its intended targets?

In general, the project achieved its planned deliverables.

Table 3: Summary of Project Deliverables Achievement

- DACC, MACC, and VACCs formed and/or mobilized.
- Mothers' Groups, male peer workers, youth and junior red cross circles, and out-of-school peer educators formed and/or mobilized.
- Counseling and home-based care and support capacity built among FCHVs, affected families, and public and private service providers.
- District officials, traditional healers, teachers, and journalists oriented on the project, and the needs for care and support.
- Referral system for linking affected families to medical services and psychosocial counseling, and linkage system to link affected families to education and skills training support established.
- One counseling centre in Mahakali Zonal Hospital and four peripheral counseling centres established.
- Limited home-base care and support available to affected families
- Existing district and community structures used for delivery.
- Public health system engaged in community-based care and support.
- Partner capacity built to support community-based HIV/AIDS impact mitigation.

It is apparent that the project's strategies, particularly those that built awareness, reduced stigma and discrimination, and mobilized communities, were successful in building an enabling environment for impact mitigation. Without this environment, a community-based care and support system would be difficult to implement. The direct involvement of community leaders in the VACC/MACCs, the support to existing community bodies, and the use of community members (i.e. Mothers' Groups, male peer workers, Red Cross Circles) as community "change agents", were successful in supporting the work of the project.

Another apparent success for the project was its ability to engage with district level officials and public service providers, particularly in the health and social services sectors, in support of community-based impact mitigation. This was done through the DACC, and through the continual efforts of project staff to involve district and public sector stakeholders.

Functioning referral (e.g. medical, counseling) and linkage (e.g. protection, education, skill development) systems exist. This was confirmed through the existence of referral slips and demonstrated on several occasions when different stakeholders demonstrated their knowledge of how others were working together with the same affected households, or how one referred a household to another². The base of the referral system is the FCHV who links an affected household to the required service. As discussed in the previous section, the effectiveness of these systems is limited by the existence, quality and accessibility of services.

The project appears to have developed a number of critical skills among its partners, and various community bodies and service providers. These skills range from basic Participatory Learning and Action (PLA) training for Mothers' Groups, allowing them to discuss HIV/AIDS, stigma and discrimination, and the role of the community in supporting households affected by HIV/AIDS, to technical training for care providers on the management of opportunistic infections and palliative care. The care and support training provided to FCHVs and members of affected families on hygiene/sanitation, when to seek medical attention for opportunistic infections (OI), lay counseling, nutrition, and basic medical care, seemed appropriate to the needs and capacities of community members. The mobilization of male peer educators, many of whom were Red Cross Volunteers, also appeared to be effective.

It is important to re-emphasize that it was not the purpose of this project to engage directly with those infected or affected by HIV/AIDS. Rather, it was to mobilize communities and local governments, and engage with service providers in the development of communitybased care and support options. As such, it was the decision at the time of project "startup" to not deal with VCT, prevention, income generation, and care and support that included drug and medical supplies provision. However, it is now important that the project revisit the issue of community-based care and support and consider how, in light of a more supportive environment and increased care provider capacity, it might develop a more complete and integrated care and support framework. Such a framework, based upon a review of work done to date, an assessment of community needs and service provider capacity, and the development of a shared conceptual understanding, would allow for a more structure approach to care and support and assist in the project's expansion. This framework must also deal with the demand for VCT, particularly since VCT has apparently recently been introduced at the Mahakali Zonal Hospital³, and may use project trained counselors for pre- and post-test counseling. The demand for income generation services should also be considered.

Lesson Learned:

A care and support system should not be developed without access to VCT.

- 1. By building community awareness about HIV/AIDS care and support, the project generated a demand for VCT in Kanchanpur District.
- 2. VCT should be used as an entry point to a care and support system, as well as for HIV prevention services, depending on the outcome of the test.

² In separate interviews, project staff, a FCHV and a sub-health port health professional all showed knowledge of the work of the other care providers with several affected households in Daijee.

³ It remains unclear as to whether VCT is offered by Mahakali Zonal Hospital as the answers given by hospital staff were unclear. It does appear that 200-300 test kits were sent to hospital in May 2003 by NCASC but whether these were for VCT or surveillance was not made clear. Counseling Centre staff has not been trained in pre- and post-test counseling.

The field visits to the central counseling centre at the Mahakali Zonal Hospital and the Dodhara Primary Health Centre (PHC) showed greatly different environments. The centre at the hospital was relatively difficult to access, physically unwelcoming, and offered no prevention services, while the centre in Dodhara was well set-up, friendly, accessible, and offered prevention services. These differences should be reviewed if the counseling centre at the hospital is to become the VCT centre for Kanchanpur. A review of the counseling training offered to project participants also indicates that it is not sufficient for pre- and post-test counseling, yet it appears likely that project trained counselors in Mahakali Zonal Hospital have/will provide this service when VCT is offered. The counseling function would benefit from access to counseling supervision and technical support.

Given these concerns about the structure of care and support, and its technical delivery, project staff has said that communities have generated many useful and replicable ideas on care and support. As discussed, an important next step is the development of these ideas into a care and support package or system for dissemination and wider application.

While no behaviour change communication (BCC) materials have yet been developed by the project, pamphlets designed through a joint care provider/people with HIV workshop are currently being printed. The NNSWA has also developed the "Mayako Thaili" (Bag of Love) for wives to send to their migrant husbands. It contains a letter containing good wishes and a cassette tape with prevention information.

Did SC/US, NNSWA and NRCS provide the necessary leadership, innovation and creativity for project success? Did project staff have the expertise and experience to carry out the planned activities?

As mentioned above, SC/US, NNSWA and NRCS have demonstrated strong skills in creating enabling environments for HIV/AIDS impact mitigation at the community level. Project staff has shown expertise at engaging district level officials and service providers in support of the project's objectives. In the areas of community mobilization and coordination and in capitalizing on opportunities for synergies with other projects and bodies, project staff has also shown leadership, innovation and creativity.

One deficiency in the expertise of project staff was their lack of technical knowledge and experience in both care and support, and counseling. Given their depth of training, they were limited in their abilities to provide technical support to care providers in the management of opportunistic infections, nutrition, palliative care and counseling. This needed technical capacity should be seen as the "referral system" for frontline care providers who need information, mentoring or support. Whether such expertise is developed within the project staff or with the office of the District Public Health Officer (DPHO) is an issue for discussion.

Did the project's structures and processes support project operations and the achievement of expected results? Were responsibility efficiently divided between SC/US, NNSWA and NRCS?

It was generally observed that the project structures and processes supported project operations. Activities were planned and delivered in a coordinated manner. Project staff from SC/US, NNSWA and NRCS understood and supported the roles and work of each other. Several stakeholders commented on this positive aspect of the project, including the Local Development Officer for Kanchanpur District, who said hat the *HIV/AIDS IMPACT Mitigation Project* was the "...most coordinated project in the district".

The involvement of the NNSWA and NRCS was also noted as a positive factor in project success because of their experience and high profile in Kanchanpur. This was a definite factor in the ability of the project to quickly mobilize communities. It was also noted that both partners went to some effort to integrate this project into their other activities, though this did cause some coordination concerns.

Several project staff commented that the coordination aspects of the project took considerable effort, and while they recognized its benefits, wondered whether there was not a simpler way. There were also concerns about the clarity of the NRCS and NNSWA roles (within the project and also with each organization's other work) as both share similar skills. This had led to some tension, particularly in cases where one partner felt that they had the ability to deliver a needed service but was restricted from doing so by the project. This is the situation that currently confronts the project over NRCS's possible involvement in home-based care and support. The project has so far showed an ability to manage these issues. The decision to move PLA training from the NNSWA to the NRCS is an example of maximizing partner skills for the benefit of the project.

Lesson Learned:

There is a need to clearly delineate the project roles of project partners when both partners have similar skills. There is also a need for an understanding between project partners on the coordination of activities, which occur outside of the project.

Some concerns were expressed that tasks were divided between the partners on the basis of past experience and not on project needs. An example of this was the project's decision to use the NRCS to mobilize the Mothers' Groups and the NNSWA to build capacity in the FCHVs (FCHVs are members of Mothers' Groups). This caused some confusion at the community level and coordination difficulties for SC/US. Joint delivery by partners to both FCHVs and Mothers' Groups or a single delivery partner would avoid this issue.

Lesson Learned:

Any project that wishes to mobilize Mothers' Groups and the Female Community Health Volunteers towards the same objectives must ensure that this mobilization is coordinated.

Another significant lesson learned by project staff was the error of not involving Maternal Child Health Workers (MCHW) in the project. From a sustainability perspective, their involvement is critical as they are the frontline community-based service providers who support the FCHVs.

Lesson Learned:

Any project that depends on the work of Female Community Health Volunteers, must also mobilize the professionals that support them: Maternal and Child Health Workers.

Did local communities and governments understand their role in the project? Did the project have an appropriate strategy to strengthen the capacity of local

institutions? Did they participate in the selection of beneficiaries and the determination of needs?

As discussed earlier, there was an initial mistaken expectation on the part of both communities and local governments, that the project would provide income generation opportunities and direct support to affected families. There was also considerable initial reluctance on the part of Kanchanpur district and community leaders to accept HIV/AIDS as a priority issue. These misunderstandings and lack of awareness required the project staff to invest considerable effort in building awareness within the DACC, MACC and VACCs, orient them on the activities and objectives of the project, and build capacity in support of HIV/AIDS community impact mitigation. These efforts appear to now be paying dividends in terms of support, participation, and advocacy on behalf of the project at district levels. With the exception of some district staff, most people interviewed, particularly at the VACC level, communicated an informed view of the project and their role in it.

As mentioned earlier, there appears to be considerable success at the use of PLA and PRA tools in building the capacity of groups like Mothers' Groups and male peer workers.

While the evaluation has questioned the lack of a formal role for people who are HIV+ and their families in the project, it is clear that the VACC/MACC have articulated the needs of people who are HIV+, and proposed activities to address these needs. All of the VACCs interviewed, also had Mothers' Groups members on the committees, and were well connected with the project activities occurring within their VDCs.

On the issue of *Greater Involvement of People with AIDS* principle, project staff said that (1) people who are HIV+ and their families were initially reluctant to come forward because of fear of stigma, and (2) that they feared that the needs of affected households were beyond the resources of the project. The project staff did see the benefit, in principle, of greater future involvement of infected and affected persons in project activities.

Lesson Learned:

Develop the awareness and the capacity of MACC/VACC to support community-based care and support before initiating care and support activities.

How did different communities respond to the development of care and support options and stigma and discrimination activities?

Project staff felt that different communities (e.g. high caste, Dalit, Tharu) did not appear to demonstrate different responses to the project or to community-based care and support. It was observed (except for one Tharu Mothers' Group) that the Mothers' Groups were a mixture of castes, and formed on the basis of proximity (neighbours).

Several project staff discussed the idea of "double discrimination" – that those who are HIV+ are more likely to face stigma discrimination if they are from a lower caste or a marginalized ethnic group, or are impoverished. This would indicate that people of different caste/ethnic backgrounds, or who are poor experience HIV/AIDS in different ways.

Did the project identify programmatic options for working with vulnerable and affected families? Were people living with HIV/AIDS satisfied with the care and support that they received?

It appears that the project was able to identify and implement a range of program options for families affected by HIV/AIDS. These options included education bursaries, job training, community provision of shelter, clothing, blankets and food, fund-raising schemes, and home-based care and support for those who are HIV+. These options were built upon the solid foundation of a positive enabling environment, created by the project's efforts to build awareness, reduce stigma and discrimination, develop capacity, and mobilize communities, local governments and care providers.

As yet, the project has not systematically reviewed and obcumented these options, in order to standardize their application. As discussed, this would be an important step should the project wish (1) to be a model for other projects or (2) to replicate and expand its own work.

The evaluators met with nine heads of households affected by HIV/AIDS. All expressed satisfaction and appreciation for the support that they had received including education support for their children, food, clothing and shelter, and training in home-based care and support. Many also stated that as a result of the project, they no longer faced the discrimination that they once did from their wider families and neighbours. They went on to give examples of how they were able to participate fully in community activities and live openly as a family affected by HIV/AIDS.

An unmet need of affected households was drugs for opportunistic infections. Another consistent concern of HIV+ parents was the future of their children, following their deaths. A future project, with some legal assistance, could provide "legacy support" to affected households.

The issue of drug provision is more complex. Given the known capacity of the public health system and the unknown but limited capacity of poor communities to protect their most vulnerable members, the provision of drugs through community-based mechanisms should be studied. Already, Daijee VACC is using its funds to support drug costs for affected households. While these funds are limited, this is an important decision by a community body about its comparative advantages and priorities.

Did the project effectively monitor its operations and the expected results?

As discussed, the management of the project would have benefited from a results framework and a monitoring and evaluation framework, which reflected its "pilot project" nature.

In addition, the development and use of several standard project management tools would have increased the ability of staff to manage the project and to monitor its progress. These include the linking of indicators to specific results, the development of a Work Breakdown Structure (WBS) and numerically ordered work packages, standardized reporting tools for partners, cumulative reporting, and financial reporting against the work packages.

Given the small size of the project, it is not felt that these issues negatively impacted the quality of the project's activities, though the use of these tools could have increased the efficiency of project management. These tools would be essential should the project be expanded.

4.1 Findings and Recommendations

The evaluation findings...

- 1. The project has successfully achieved its deliverables and reached the targeted beneficiaries. This success can be attributed to the project's strategy of awareness building, mobilization, and development of district bodies, community organizations, and care providers throughout the life of the project. This was essential to develop district and community level support and advocacy for the project. The building of partner and care provider capacity, the use of experienced local partners, and the efforts expended on coordinating stakeholders were also important factors.
- 2. The project, through its work to reduce stigma and discrimination, has created an opportunity for people who are HIV+ and their families to become fuller participants in the process of both defining their status as beneficiaries and determining their needs.
- 3. Because of the large number of stakeholders involved and the use of referrals and linkages to match affected households with needed services, large coordination efforts were required.
- 4. Any project that mobilizes FCHVs should also mobilize Maternal and Child Health Workers (MCHW), as the primary support structure for the FCHVs.
- 5. There is an opportunity for a community-based impact mitigation project to provide affected households with "legacy support", helping terminally ill parents to plan for their children's well-being and future (e.g. guardianship, inheritance, family unity).
- 6. Pilot projects need to be explicitly designed as such: formalizing and documenting learning. Without this explicit understanding, project staff is committed to the implementation of project activities, without the parallel obligation to reflect on their implementation in an organized and systematic manner.

The evaluation recommendations...

- 1. The project staff of the HIV/AIDS Impact Mitigation through Mobilizing Affected Communities Project should conduct a facilitated review exercise to analyze and document the experiences of this project, and suggest how the programming approaches used could be replicated or expanded. Such a review should also identify the unmet needs of affected and vulnerable households.
- 2. Any future major impact mitigation project in Kanchanpur should include (1) a needs assessment of care and support requirements, (2) the development of a shared understanding of community-based care and support, and (3) a framework to assist communities to develop their own options and to set priorities for resource allocation. A clear linkage should also be established with VCT and prevention programming. Such a future project must be built upon a base of aware, supportive and mobilized communities and district stakeholders.
- 3. Any future major impact mitigation project in Kanchanpur should include the development and availability of technically proficient and experienced staff to train and support community- and home-based care-providers (including counselors). Such expertise could be developed either within district-based project staff or within the office of the DPHO. There is a need for the counseling centre at the Mahakali Zonal

- Hospital to become more accessible and physically welcoming, and able to offer prevention services.
- 4. Any future impact mitigation project in Kanchanpur should include the capacity building of MCHWs and the development of "legacy support". Any future referral system should include links to adjacent Indian testing and treatment facilities. This would be particularly important for Chandani and Dodhara VDCs, where people normally access Indian health services because of their proximity.
- 5. Any future impact mitigation project Kanchanpur should involve affected households in project implementation, including governance and delivery. Specific activities for consideration include the employment of people with HIV in the project, the use of HIV+ volunteer peer workers, the establishment of a project advisory group of affected households, and the use of participatory monitoring and evaluation methodologies with beneficiary affected households.
- 6. Any future major impact mitigation project in Kanchanpur should integrate the lessons learned from this project on the use of local partners, including role delineation.
- 7. Any future major impact mitigation project in Kanchanpur should develop and apply standard project management tools and ensure partner compliance with these tools.

5. Impact

Has the health and well-being of targeted households improved? Has the vulnerability of targeted households been reduced?

While it is too early to quantitatively judge the project's impact on the health and well-being of affected households, it is apparent from discussions with affected households that there has been a positive impact. Household heads described reduced stigma and discrimination, and increased acceptance from the community and wider family members, as well as renewed participation in community life. They also described the importance of the counseling, and the care and support that their households received, as well as the support to meet basic household needs. One FCHV described how a Mothers' Group had recently confronted a teacher about his discriminatory behaviour towards the children of an infected woman who was also a member of their group. Such support appears to maintain family unity and reduce vulnerability to opportunistic infections, the spread of HIV, school absence, family fragmentation, and child labour.

Household vulnerability was also addressed by the decisions of local government bodies to increase public funding for community-based impact mitigation activities, primarily funding from the DCC to the DACC and VACC/MACCs. The actions of these bodies appear to indicate a high priority given to impact mitigation.

This reduction of household vulnerability also appears to be evident through the requests of participating VDCs to expand the project into their jurisdictions, and the desire of the DACC and other VDCs to replicate the work of this project throughout Kanchanpur.

Affected households and community members described a growing demand for VCT and the drugs required to treat opportunistic infections. Community bodies and project staff said that this is a result of mobilizing communities and is an unintended impact of the project.

An overall lack of community resources is the largest limitation to reducing the vulnerability of affected households. The lack of prevention services, particularly for migrant men, also increases the vulnerability of all households to HIV/AIDS.

Do local NGO partners have an increased capacity to facilitate and support community efforts to provide care and support to people with HIV/AIDS and their families, including children?

As discussed, it is evident that NRCS and NNSWA have the capacity to mobilize and support communities to develop the enabling environments required to help communities mitigate the impact of HIV/AIDS. It is also clear that partner capacity was developed to support the provision of community-based care and support to affected families, including counseling. There are, however, some concerns about the level of partner technical expertise required to sustain a community-based care and support system, including counseling.

Have there been positive changes in the communities' behavior regarding stigma and discrimination?

There is evidence that the project significantly reduced the stigma and discrimination experienced by affected families, through its awareness and mobilization activities. The nine households interviewed were explicit in the their descriptions of the stigma they felt and the discrimination they suffered prior to the project, and how the work of the project

had allowed them to rejoin their communities and families. This process of rejoining meant the ability to live openly with HIV in their community, to participate in community events, and to feel free of shame and discrimination, which had included physical and social isolation and the threat of violence. Discussions with VACCs and Mothers' Groups also revealed that many have women from affected families as members.

Community members who were not directly affected, indicated that the awareness building done by the project had brought them to the position where HIV/AIDS was seen as a disease and not as a judgment on the morality or value of the affected households. The evaluators were also able to meet with community members, who, as a result of awareness building, were now directly assisting affected households. It should be noted that these community members were people who had had some interaction with the project and it is impossible, without the use of survey techniques, to definitively determine wider community behaviour.

However, the evaluators observed people living openly in their communities, as infected and affected people, something that was not possible at the beginning of the project. This change creates future opportunities to engage such people as peer educators and staff in an expanded community-based care and support project, and to mobilize self-support groups for infected and affected people.

Do communities have an increased capacity to support households affected by HIV/AIDS?

There are numerous encouraging signs that communities have increased their capacity to support households affected by HIV/AIDS.

Table 4: Summary of Achievements in Building Community Capacity

- The DDC and VDCs have increased the level of funding to the DACC and VACCs. The DACC and VACCs have increased their programming and in the case of the VACCs, they are raising money from their communities.
- Male peer workers are raising community funds to assist affected families.
- A group of teachers are proposing the establishment of a fund comprising of 2% of teachers' salaries to support orphaned and vulnerable children, many of whom would be affected by HIV/AIDS.
- DACC and the VACCs/MACC meet regularly and discuss ways in which the communities can be mobilized to support households. This includes advocating for increased funding and making linkages to resources (e.g. educational bursaries) and paying for drugs to assist affected families.
- Community members, including male peer workers and the Mothers' Groups/FCHVs are using the skills developed through PLA and PRA training to assist affected families and to build awareness in the wider community.
- FCHVs have increased skills to support home-based care and support and to refer people with HIV to medical and counseling services.

The development of increased community capacity to support affected household has created some concerns about coordination and the ability of community groups to set priorities and plan. This is a natural outcome of building awareness and supporting mobilization – communities wanting to act, using their resources. However, it is apparent that many VACCs still need to develop their abilities to assess needs, and to make choices on how best to use their limited resources. The building of planning capacity should be a logical next step.

Given the poverty of the project's target communities, it would also be advisable to better understand the limits of support that poor communities can provide to vulnerable households. This task could be included in a future initial assessment.

5.1 Findings and Recommendations

The evaluation findings...

- 1. The project has appeared to reduce the vulnerability of affected households and increase their well-being. Partner NGOs and community bodies exhibited newly developed capacity to support community efforts to assist affected households.
- 2. The project's work to reduce stigma and discrimination was critical to developing the enabling environment required for communities to mitigate the impact of HIV/AIDS. The use of PLA and PRA methodologies were an important component in increasing awareness, and reducing stigma and discrimination. This has created an opportunity for a fuller involvement of people with HIV and their families in the project.
- 3. Involvement of local government and community bodies was important to create ownership of community-based impact mitigation activities.
- 4. An unintended impact of the project's awareness building and stigma and discrimination reduction efforts was an increased community demand for VCT and increased care and support, including drugs for opportunistic infections.
- 5. An unintended impact of the project's community mobilization activities was the desire of community bodies (i.e. VACC/MACC) to engage in impact mitigation activities using their own resources. It would be important next step to develop the capacity of these bodies to formally engage their communities to assess needs, set priorities, and make plans on how to best use these limited resources. It would also be important to further develop their capacity to coordinate with community and external bodies.

The evaluation recommendations...

There are no recommendations specific to this section, though recommendations on involvement of affected households, community and stakeholder involvement and mobilization, reduction of stigma and discrimination, increased community demand for more services, and sustainability of community mobilization, are found in the **Relevance**, **Effectiveness/Efficiency**, and **Sustainability** sections of this evaluation report.

6. Sustainability

Was the project's strategy appropriate and sustainable? What would make it more sustainable?

As a "pilot project" of 18 months duration and limited funding, it is difficult to discuss sustainability. However, it does appear that the project's strategies have achieved considerable success in building awareness, creating supportive and non-judgmental community environments, mobilizing communities and local governments, and building partner, community and care giver capacity. These successes, though, have only recently been realized, and may fade without more resources and time to "set" these results in the communities. There is also a need to document and standardize the approaches and lessons of this project, if it is to be expanded in Kanchanpur or replicated elsewhere.

There are several challenges with regard to sustaining the positive results of this project.

- 1. The capacity of poor communities to support vulnerable and affected households will continue to be tested. While the project has done a commendable job on helping communities to find the resources to deal with the current numbers of affected households, it is uncertain what number of households could be supported in the future, as the number of HIV infections grows. This issue should be considered in the development of any future community-based impact mitigation project.
- 2. With reference to the caring capacity of poor communities, there is a need to caution against reliance upon a charity model. While it is commendable the local bodies are focusing on fund raising, it is questionable whether this is sustainable. A self-help model, where community members are encouraged to both increase their advocacy efforts and provide for their vulnerable neighbours using resources readily available in the community food, building materials, and labour, as well as money if available, is more sustainable.

There is a ongoing need to build the capacity of community bodies to assess local needs, set priorities, and plan for the use of their limited resources, in a manner which increases impact and supports sustainability. To this end, the sole focus of allocating funds for the assistance of individual affected households, while commendable, is not necessarily the best use of these funds. A community need identified in this evaluation was drugs for opportunistic infections and palliative care. Following the lead of Daijee VACC, other VACC/MACCs might also be encouraged to establish funds to pay for a stock of necessary and commonly used drugs. Funds could also be established to support the work of the FCHVs, and to sustain their mobilization.

- 3. The ability to mitigate the impact of HIV/AIDS is limited without income generation and employment opportunities. The Chief District Officer emphasized this point.
- 4. The mitigation of the impact of HIV/AIDS on families is limited in the absence of Prevention of Mother-to-Child Transmission (PMTCT) guidelines and access to PMTCT treatment. The evaluators met several families with children under the age of four, whose parent(s) had already died of (suspected) AIDS, and were themselves exhibiting AIDS symptoms. It is expected that the NCASC will soon release PMTCT guidelines and that a funded national program will make PMTCT treatment available to pregnant women who are HIV+.
- 5. There are limits to the use of community volunteers, particularly FCHVs, in the delivery of care and support activities. The sustainability of this project depends upon the

- ability to use this resource in an efficient manner. There is a need to look at the capacity of the VACCs to support volunteers (e.g. ability of VACCs to reward FCHVs).
- 6. There is a need to engage the public health system on the provision of resources and personnel⁴. This presents several challenges that extend far beyond this project, and focus on the absence of a functioning public health system in many parts of Nepal.
 - District and community leaders made several comments on the lack of an ongoing relationship with NCASC. This must be built, as the National HIV/AIDS Programme is operationalized, and DACCs are given increasing responsibility and funds.
- 7. Several district and community leaders recognized the need to deal with increasing numbers of orphaned and vulnerable children (OVC). However, their focus was on the development of institutional care and not on keeping children in their communities. While institutional care is important, it should always be a temporary or final option. As discussed, a project such as this, has an opportunity to develop "legacy support" options and to work with affected families to plan for the future of their children.
- 8. There is an opportunity for the project to now take a more systematic approach to the provision of community-based care and support, to document the lessons learned, and propose a model or framework based upon the project's experiences. There is also a need to sustain such work with the future provision of technical support in care and support, and counseling. Access to VCT, and access to drugs for opportunistic infections and palliative care, are also required to sustain the referral system.

To what extent has the project established sustainable linkages among local groups?

To the extent that it could be observed, sustainable linkages were established among local groups. Affected family members were participating in Mothers' Groups and VACCs. FCHVs, Mothers' Groups members, and male peer workers were sitting as members of the VACCs. The project also appeared to have been well integrated into the other work of the partner NGOs, including the local Red Cross chapters.

FCHVs often meet at the VDC level. There is now an association of Kanchanpur FCHVs.

To what extent will the project partners and beneficiaries be able to take charge of the project's objective after the project is completed and funding withdrawn? Is the phase-out strategy appropriate and supportive of other strategies?

At the community level (VACCs, Mothers' Groups, FCHVs, male peer workers), there is a consistent opinion that the work of impact mitigation will continue, within the limits of community resources. The project is credited with developing this capacity. This would include continued awareness raising, fund raising, mobilization activities, and limited community-based care and support. DACC, VACC/MACCs, Mothers' Groups, male peer workers, and Red Cross Circles will continue to meet and plan community awareness and mobilization activities, local funds will continue to be solicited, and FCHVs will continue to deliver home-based care and support. However, the lack of community resources will restrict the scope of their work. Many expressed the opinion that 18 months was not

⁴ A consistent concern of FCHVs was the unstable nature of public care owing to high staff transfer rates and public health staff who were not at their posts. These issues speak to systemic problems, which go far beyond this project.

enough time to sustain the results. In addition, it appears that the DACC and MACC/VACCs still need to build their capacity to plan activities and allocate resources.

All four project VACCs now have annual budgets greater than the NR 10,000 required in the Monitoring and Evaluation Framework, ranging from NR 20,000 to NR 50,000.

The DPHO said that counseling services at Mahakali Zonal Hospital, now supported by the project, would not be supported by the district's budget in the future.

There is no phase-out strategy for this project. SC/US is currently proposing a threemonth extension from its own funds to search for resources to continue and expand the project.

Could this project be replicated elsewhere? Could it be "scaled-up" or expanded?

The district has requested that the project be replicated throughout Kanchanpur, with differing views as to the process⁵. The project has been unable to support this growth due to funding restrictions, though some limited replication has occurred in one VDC next to Jhalari.

Replicating the current project could probably be accomplished with only a small increase in the current resources. This replication would also continue the focus on community mobilization and capacity building. It would also, most probably, generate a similar increased demand for VCT and a broader community-based care and support program.

The expansion or "scale-up" of the project would require a larger investment and longer period of time. It would need to be based on a similar model of community mobilization but should also include (1) VCT, prevention and income generation components (and referral and linkage systems to them); and, (2) a broader care and support component with an initial needs assessment, a framework for service delivery, and strong technical support.

6.1 Findings and Recommendations

The evaluation findings...

- 1. Community and local government bodies have expressed willingness and demonstrated an ability to carry on the work of the project (with the exception of the central counseling centre) within the limits of their capacity and resources. There remains some concern of the planning capacity of community bodies to assess community needs, set priorities, and commit resources.
- 2. There is a need for more time and resources to "set" the project's successes.
- 3. There are concerns about the ability of poor communities to deliver impact mitigation services, including community-based care and support, as the epidemic increases in size. Community reliance on fund raising and a charity model may not be sustainable given the limited funds available in the community. There are also concerns about the level of responsibility that can be placed on community volunteers to deliver services.
- 4. Sustainability of the project is threatened by a lack of income generation and employment opportunities.

⁵ Some believe that the project should be quickly expanded to the entire district while others, including the CDO, want an initial expansion to four-five VDCs on the Indian border.

- If the project were to be expanded, there would be a need to systematically develop the services required by the community and to ensure their delivery either within or outside the project.
- 6. With the project focus on the creation of an enabling environment, it is inevitable that community demand for impact mitigation will increase. As such, the sustainability of this project is linked to the ability to expand the project to include these needed services. The replication of this project in other parts of Kanchanpur District would result in increased demands for these services.
- 7. Despite past challenges, there is a need to fully engage the public health system. The ongoing operationalization of the *National HIV/AIDS Strategy* may provide some direction and support in the areas of prevention of HIV/AIDS among migrants and their families, VCT, PMTCT, protocols on the management of opportunistic infections, and social protection for people who are HIV+ and their families.

The evaluation recommendations...

- 1. Any future impact mitigation project in Kanchanpur District should continue to build the capacity of community bodies to plan. This includes the capacity to assess needs, set priorities and commit resources, as well as coordinate with stakeholders.
- 2. Any future major impact mitigation project in Kanchanpur should assess the capacity of poor communities to support an increasing number of affected households. An assessment should also be conducted on the level of responsibility that should be placed upon community volunteers and what support systems are required.
- 3. Any future major impact mitigation project in Kanchanpur should review the linkages between the project and the public health system, including the NCASC. As elsewhere, there is the dilemma of whether to build the capacity of an underperforming system or to build local capacity outside or parallel to the public system. This includes questions of whether communities should be generating funds for OI treatment, or NGOs should be delivering care and support, counseling and VCT services. These issues go far beyond this project but should be addressed in the absence of a response from the public health system. The project should be prepared to create synergies with the impending operationalized National HIV/AIDS Strategy.
- 4. Any future impact mitigation project in Kanchanpur should move community bodies and volunteers from a primary focus on fund raising, to one that includes advocacy and the promotion of self-help, better using existing community resources. Following the example of Daijee VACC, more analysis is needed on the use of community resources to pay for the drugs required for opportunistic infections and palliative care.
- 5. Any future impact mitigation project in Kanchanpur should be an <u>expansion</u> and not a <u>replication</u> of this project. Given increasing awareness and the resulting increasing demand for services, an expanded project should ensure that VCT, prevention services, expanded community-based care and support, and income generation and employment opportunities are available. Such an expansion should be built upon the awareness, acceptance, built capacity, and mobilization of the current project, but should also involve a more systematic needs assessment, a framework for service delivery of community-based care and support, and technical support to care providers.

7. Conclusion

It is the view of the evaluators that the project has, with the exception of the replication of project approaches throughout Kanchanpur District, substantially achieved the objectives set for it in the initial project documents, as articulated in the **Immediate Results** and **Expected Impacts** listed below.

Intermediate Results:

- 1. Program options to work with families vulnerable to HIV/AIDS identified by migration.
- 2. Increased capacity of local NGOs to facilitate and support community efforts to provide care and support for people living with HIV and their families, including children.
- 3. Increased capacity of the community to support households affected by HIV/AIDS.

Expected Impact (at the end of 2 years):

- 1. Increased access and utilization of counseling and care (institutional and home based) services by PLWHAs and their families
- 2. VACCs have developed and instituted (structures and systems in place) realistic plans for protection, care and support of vulnerable and/or affected households
- 3. District level and peripheral level counseling services and referral system set up
- 4. DACC/DDC replicate the project approaches in other VDCs of Kanchanpur District.

The main accomplishment of the project was the development of a "platform" upon which to build a community-based care and support program. Without efforts to build awareness, reduce stigma and discrimination, build capacity, and community mobilization, it is unlikely that a sustainable community HIV/AIDS impact mitigation response could ever be built. Having said this, it should also be recognized that a sustainable response is an expanded response, including HIV/AIDS prevention, income generation, and a more systematic approach to the development and delivery of community-based care and support services.

It is critical that project staff take immediate steps to document their efforts and to analyze the successes of their work and the challenges that they faced. Such an analysis should be developed in the context of lessons learned for similar future projects.

Appendix A: People, Groups and Facilities Visited

Prior to Field Visit People/Group/Site

Location

Tara Karki Chettry, HIV/AIDS Program Officer, SC/US

SC/US Office, Kathmandu

Naramaya Limbu, Health Team Leader, SC/US

SC/US Office, Kathmandu

Keith Leslie, Director, Himalayan Field Office, SC/US

SC/US Office, Kathmandu

Dr. Jesper Svendsen, Senior Technical Officer, FHI

Stephanie Sulowatsky, Program Coordinator, FHI

FHI Office, Kathmandu

Sunday June 1, 2003

Lok Raj Bhatta, Project Coordinator, SC/US

SC/US Regional Office, Nepalgunj

Ganga Thakali, Regional Program Manager, SC/US

SC/US Regional Office, Nepalgunj

Monday, June 2, 2003

Manoj Bhatta, Project Coordinator, NRCS NRCS Office, Mahendra Nagar Lev Dav Joshi, Blood Bank Technician, NRCS NRCS Office, Mahendra Nagar Ashok B. Jairu, Executive Director, NNSWA NNSWA Office, Mahendra Nagar Bhim B. Sinal, Project Coordinator, NNSWA NNSWA Office, Mahendra Nagar Dr. Dil B. K.C., Director, Mahakali Zonal Hospital Mahendra Nagar Khagindra Bhatta, Health Officer/Counselor, Counseling Mahendra Nagar Centre, Mahakali Zonal Hospital Dr. Subesh Raj Kyastha, Physician, Mahakali Zonal Hospital Mahendra Nagar Dr. Bal Bahadur Mahat, DPHO, Kanchanpur District Mahendra Nagar Jaya Mukand Khanal, CDO, Kanchanpur District Mahendra Nagar Binod Singh, LDO, Kanchanpur District Mahendra Nagar Affected Family (5 – grandmother and four grandchildren; 2 Bankatti, Mahendra Nagar youngest grandchildren suspected of being HIV+) Bhari Singh and Sita Singh, FCHVs Bankatti, Mahendra Nagar

Tuesday, June 3, 2003

Mothers' Group (22)

Mothers' Group (23) Chandani VDC Male Peer Workers (4) Chandani VDC Affected Woman and Mothers' Group member Chandani VDC Woman suspected of being HIV+ (2) Chandani VDC Peripheral Counseling Centre, Primary Health Centre Dodhara VDC Youth Red Cross Circle, Laxmi School (28) Dodhara VDC VACC (14); Chair: Sher Bahadur Budha Dodhara VDC VACC (17); Chair: Ragu Nath Sunar Chandani VDC Chandani VDC Traditional Healer

Bankatti, Mahendra Nagar

Wednesday, June 4, 2003

Mothers' Group (18)	Daijee VDC
Woman suspected of being HIV+ and her 4 children; youngest child is also suspected of being HIV+	Daijee VDC
Bishna Khadka, Community Mobilizer, NRCS	Daijee VDC
Mothers' Group (21)	Daijee VDC
Woman suspected of being HIV+ and Mothers' Group member	Daijee VDC
Community members and neighbours of woman above (8)	Daijee VDC
Sataya Devi Sunar, FCHV	Daijee VDC
VACC (10); Chair: Indra Bahadur Malla	Daijee VDC
Ganesh Joshi, Counselor/Nurse, Peripheral Counseling Centre, Health Post	Daijee VDC
NNSWA Field Office	Jhalari VDC
VACC (14); Chair: Chet Raj Bhatt	Jhalari VDC
Male Peer Workers (9)	Jhalari VDC
Traditional Healer	Jhalari VDC
FCHVs (24)	Jhalari VDC
Mothers' Group (20)	Jhalari VDC
Affected Family; uncle and the 4 children of his brother and sister-in-law confirmed dead of HIV/AIDS; youngest 2 children suspected to be HIV+	Jhalari VDC

Thursday, June 5, 2003

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Mothers' Group (21)	Ward 7, Mahendra Nagar
One widow suspected of being HIV+ and one woman with a husband confirmed HIV+; members of Mothers' Group	Ward 7, Mahendra Nagar
Youth/Junior Red Cross Circles (34)	Tilachour, Mahendra Nagar
Bhim B. Simal, Project Coordinator, NNSWA	NNSWA Office, Mahendra Nagar
Sher Bahadhur Rana, Project Manager, CARE Nepal	Care Nepal Office, Mahendra Nagar
Manoj Bhatta, Project Coordinator, NRCS	NRCS Office, Mahendra Nagar
Stakeholder Debriefing	Mahendra Nagar

Friday, June 6, 2003

Lok Raj Bhatta, Project Coordinator, SC/US Mahendra Nagar

Appendix B: Summary of Deliverables to Date

Deliverable	Number
Mothers' Groups Mobilized	200
Mothers' Groups Members	4000
FCHV Mobilized – Care and Support	200
FCHV Mobilized - Counseling	100
Male Peer Workers Mobilized	160
Youth/Junior Red Cross Circles Oriented	40
Red Cross Circle Teacher Leaders Oriented	80
Out-of-School Peer Educators Mobilized	12
Traditional Healers Oriented	50
Public Health Care Providers Oriented and Trained – Care and Support	20
Public Health Care Providers Oriented and Trained - Counseling	8
Private Health Care Providers Oriented and Trained	24
People with HIV or Family Members Trained in Home-Based Care	30
DACC,VACC/MACC Members Mobilized	47